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TITLE: Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI

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14. ABSTRACT
The investigation has two aims. The first is to identify risk factors associated with loss of neurogenic bladder and bowel which may increase medical and psychosocial complications after SCI. The second aim is to determine the influence of bladder and bowel management, complications and psychosocial and behavioral factors on quality of life (QOL). A mixed method approach is being used for data collection and analysis. Qualitative individual interviews have been conducted with two groups of participants: persons with SCI (target N=40) and caregivers (target N=20). Interviews are supplemented by quantitative measures to evaluate the extent and severity of bowel and bladder related health problems and quality of life ratings. The project will evaluate differences between a civilian and military cohort. Significant data collection took place at both sites (UM and VA) during Year 2. At the time of this report, 52 (of 60) interviews have been completed. Forty-five participants (SCI and caregiver) were successfully recruited and interviewed during this second year. Data collection has been completed at the UM site. A few more interviews need to be conducted at the VA site (4 persons with SCI and 4 caregivers). We have recruited participants to complete data collection and are currently scheduling interviews with these participants. Additionally, 20 persons (10 SCI and 10 caregivers) will participate in focus groups, making a total sample of 80. Planning for focus groups will begin during the first months of Year 3, to be conducted beginning Month 30. The second year included a refinement of the proposed coding scheme with input from consultants (Duggan and Lequerica) and collaborator Anna Kratz Ph.D. Two new coders were hired and trained. Coding has been proceeding at a fast pace, with 28 SCI interviews coded (of 40 total by project's end). Caregiver interview coding will begin in Month 25. Having these data available will allow us to prepare future publications and presentations. Deliverables included the development of a coding book for the project and two presentations made with the 52nd meeting of the International Spinal Cord Society (ISCoS). The project advisory council met during this second year, discussing progress and advising the project moving forward.

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Introduction

The current investigation has two aims. The first is to identify risk factors associated with loss of neurogenic bladder and bowel which may increase medical and psychosocial complications after SCI. The second aim is to determine the influence of bladder and bowel management, complications and psychosocial and behavioral factors on quality of life (QOL). A mixed method approach is being used for data collection and analysis. Qualitative individual interviews have been conducted with two groups of participants: persons with SCI (N=40) and caregivers (N=20). Interviews are supplemented by quantitative measures to evaluate the extent and severity of bowel and bladder related health problems and quality of life ratings. The project will evaluate differences between a civilian and military cohort. Significant data collection took place at both sites (UM and VA) during the second year of the grant. At the time of this report, 52 (of 60) interviews have been completed. A large number of interviews with participants and caregivers were conducted during this second year. Data collection has been completed at the UM site. A few more interviews need to be conducted at the VA site (4 persons with SCI and 4 caregivers). Additionally, 20 persons (10 SCI and 10 caregivers) will participate in focus groups, making a total project sample of 80. Planning for focus groups will begin during the first months of Year 3, to be conducted beginning Month 30. By evaluating a distinct military cohort, we are able to address questions about: how these two groups cope with these losses? Are their rates of complications different? And do they report different levels of QOL? Potential treatment recommendations will be made accordingly. The second year of the project included a refinement of our qualitative methodology and extensive revisions of the proposed coding scheme with input from consultants (Duggan and Lequerica) and collaborator Anna Kratz Ph.D. Two new coders were hired and trained. Coding has been proceeding at a fast pace. Having these data available will allow us to prepare future publications and presentations. Deliverables included the development of a coding book for the project and two presentations made with the 52nd meeting of the International Spinal Cord Society (ISCoS). The project advisory council met during this second year, discussing progress and advising the project moving forward.

Body

The body of this report is a narrative serving to outline the tasks and work performed during the second year of the project. It is divided into six sections, as per our approved Statement of Work. This report is focused on Year 2 (Months 13 to 24), between 10/1/13 and 9/30/14. Relevant materials from Year 1 are retained for clarity.

1. Administrative tasks

Tasks include those being performed at the different sites as well as project start-up and recruitment of personnel; coordination with work sites; re-submission of IRBs; meeting with advisory committee members; maintaining relationships with Department of Defense CDMRP and SCI program representatives, PM&R grant administration budget reviews; hiring new coders and coordinating and overseeing consultants' involvement across sites. Three sites are involved: 1) University of Michigan/Dept. of Physical Medicine and Rehabilitation (lead site/PI: Tate); 2) VA Ann Arbor Healthcare System (site PI: DiPonio); and Michigan Paralyzed Veterans of America (site contact: Michael Harris). This third site serves exclusively the function of recruitment, dissemination and guidance to project activities. Mr. Michael F Harris, Executive Director of MPVA has agreed to serve on the Steering Committee or Advisory Board for this project. Research is to be conducted at the first two sites listed. (Months 1-36) Year 1 activities include those from1-12 months; Year 2 includes those from 13 to 24 months. This report reflects mainly Year 2 activities.

1a. Project start-up activities (Months 1-6)
Start-up activities were conducted successfully during Year 1 (see Year 1 annual report for details). Additional activities completed during Year 2, that fall under "administrative tasks", are described below.

Year 2 activities:
A review of our accomplishments on Year 1 and of proposed timelines was conducted in Month 13 to begin planning for Year 2 activities. The project PI and the Study Coordinator met weekly to discuss progress and plan new activities. The PI began communicating with the advisory council members, orienting them about the project and addressing any questions prior to meeting. Advisory board or Steering Committee members were contacted and asked to confirm their interest in participation. They were sent information about this project and a meeting was held in Month 18 (March 21st 2014). Members included: Michael F Harris, MPVA Executive Director and someone with a SCI himself; Sandy Loyer, past UM-SCI social worker for over 20 years and currently a consultant to Department of Army to assist returning soldiers and their families with adjustment issues; Dr. Mark Luborsky, a medical anthropologist with extensive experience in qualitative methods and Dr. Cathy Lysak, Associate Professor at Wayne State University with an occupational therapy background and experience in SCI care and research and also an experienced qualitative methodologist. All members participated in the council meeting, providing considerable input and demonstrating their interest and commitment to the project. Drs. Werner and Chiodo were dropped from the original list of potential members since the project already has a strong physician representation among Drs. DiPonio, Cameron and Rodriguez. Dr. Rodriguez and DiPonio see SCI patients at their clinics at UMHS and VA and Dr. Cameron treats those with SCI with bladder problems at her UM-Urology clinic. She too is familiar with the VAMC in Ann Arbor where she served as a fellow initially. The meeting provided crucial input on our overall project activities, recruitment, conceptualization and design of the project, and dissemination activities. The qualitative methodologists in the council were able to guide us towards some additional ideas for analyzing our data and making good use of our upcoming focus groups. Their recommendations included 1) doing a refined comprehensive

review of the literature in order to develop a parallel coding scheme to identify areas of our dataset that can directly contribute to gaps in the SCI literature; 2) compare our quantitative results with those of national samples with SCI in relation to QOL to better contextualize our findings, 3) target focus groups to understand episodic experiences of bowel and bladder complications impacting QOL. An additional advisory council meeting is being considered for Spring 2015 (near Month 30). A number of action items and recommendations were identified during this meeting:

1. Rohn will continue to follow up with Hoatlin and Harris for recruitment opportunities. Once identified and contact information obtained, he continue follow up to those directly involved with potential SCI participants and caregivers.
(This task assisted us in the significant progress made in data collection during Year 2 and continues to help in our recruitment.)

2. Rohn and Tate will conduct a systematic review of the literature to fill in gaps in our literature review but also to identify salient issues as well as gaps in the literature. Our data can be coded to directly address these.
(This task is currently in progress.)

3. Identify viable larger datasets for comparing and contextualizing our quantitative samples. Forchheimer identified as most able to assist Rohn in this.
(This task will be untaken once data coding is complete.)

4. Interviewing will attempt to be less formal moving forward, allowing the participants more latitude to convey to us the salient issues in their quality of life.
(This approach has significantly increased the richness of the qualitative data collected.)

5. Focus groups will focus on episodic incidents as fuel for conversation. Focus groups should be about the interactions and not be treated as "mini-interviews". The hope is to identify a number of "scripts" – with these and the interviews – that will help illustrate the consonance and/or discordance of our sample as compared to the literature.
(This recommendation will be instrumental as we plan our focus groups.)

Recruitment and hiring of coders for Year 2 activities (new activity):
Roxanne Madrid, MA and Emily Zafiroff, BA were successfully recruited and hired to begin using our revised SCI coding schema and begin coding all SCI transcripts. An inter-rater reliability study was conducted. Ms. Madrid and Ms. Zafiroff worked with Study Coordinator Rohn to code a single transcript. The three person team met with Principal Investigator Tate to describe the work that was done. Percentage of agreement was calculated on this transcript; all items were in at least 80% agreement (and often over 90%), where 70% and above is considerable standard and acceptable. Further, the disparities could be partially explained by the sensitivity of NVivo 10's comparative approach: extra blank lines or other non-data elements coded within the text are counted as significant. Therefore, our 80% coder agreement could be much higher given this sensitivity. Further inter-rater reliability checks are scheduled for Month 25, 27, and 29.

1b. IRB and other regulatory approvals required by UM, VA and CDMRP (Months 2-6)
The IRBs for both sites were prepared, resubmitted and approved during Year 1.

<u>Year 2 activities:</u>
Continuing reviews for both sites were prepared, submitted and approved for Year 2 (UM Month 24; VA Month 15). Continuing review deadline for the VA for Year 3 is approaching and will be completed in Month 27.

1c. Submission of research reports to the Department of Defense (Months 11, 24 and 36)
All quarterly reports were submitted as required, on 31 Dec 2013, 31 March 2014, and 30 June 2014. As instructed, the present annual report stands as the research report for our quarterly report due on September 2014 (month 24).

1d. Consultants agreements/scope of work and timelines confirmed (Months 1-3)
This activity was successfully conducted during Year1. Year 2 activities included meeting with consultants Drs. Duggan and Lequerica. Payments were processed accordingly.

1e. Establishment of DSMB (Data Sharing and Management Board) (Months 3-6)
The project is not a clinical trial or intervention study and does not require a DSMB.

1f. Contract with transcription services (Months 3-4)
During the first year, data transcription services were secured for the UM arm of the study through a private company (Datagain) with UM IRB consent, signed non-disclosure agreements, and a payment system established through the PM&R grant administration office. The VA transcriptionist services were set up by hiring a private temporary employee who was already approved to work at the VA. Sarah Steffens, BS was hired in a temporary capacity to complete transcription on the 30 VA interviews. As of this report, she has transcribed all available VA interviews (N=22).

<u>Year 2 activities</u>:
Transcriptionist services worked very well and transcriptionists were paid accordingly.

1g. Payment for subject fees for participation (Months 6-30)
Subject fees have been paid as SCI participants and caregivers completed data collection activities, beginning in Year 1 and continuing throughout during Year 2. This task will continue throughout the length of data collection, including focus groups, anticipated to end by Month 33.

2. Research Design
For Year 1, tasks included refinement of the new coding schema for SCI participants, discussion of steps required for both the qualitative and quantitative aspects of the study; establishment of a database for quantitative data collected; and systematic review of the literature (Months 1-10)

2a. Development, refinement and review of interviews and study measures (Months 1-3)
This activity was successfully conducted during Year 1.

2b. Pilot of measures and interviews with SCI participants and caregivers (Months 3-4)
This activity was successfully conducted during Year 1.

2c. *Refinement of Bladder and Bowel Diary format and reporting forms (Months 3-5)*
This activity was dropped as it was felt that it would duplicate work being done already by the UM SCI Model System program. This was discussed in a letter to the sponsor addressing reviewers concerns to avoid duplication of efforts between this newly funded project and the UM

SCI Model System project funded by National Institute on Disability and Rehabilitation Research.

2d. Development of databases in word, Excel, SPSS, and NVivo (Months 5-10)
This activity was successfully conducted during Year 1. Databases have been instrumental in the tracking and storage of data collection, implementation of our coding procedures, and will be crucial now as our analysis begins.

2e. Review of plans for data sharing and dissemination of products (Months 7-10)
Because the project start date was delayed due to VA IRB issues this activity was not completed during the first year. These were addressed during Year 2. See relevant "dissemination" and "reportable outcomes" sections below for more discussion.

Year 2 Activities:
Refinement and review of the project coding scheme (Months 15-18)
Following discussions with project collaborators, investigators, consultants and staff it was decided that the proposed coding schema did not capture the range of psychosocial factors associated with the problem being studied. The team revised the coding schema to more comprehensively reflect these factors. A complete revised coding book for SCI subjects was developed by Study Coordinator and colleagues during Months 15-18. See attached. A separate caregivers-focused coding scheme may be necessary and will be developed during Months 26-30. We will attempt to implement the current coding scheme to caregiver interviews, with minor revisions as necessary.

The development of a refined and rigorous coding scheme is instrumental in effective and valid qualitative data analysis. Over the course of three project-wide meetings and numerous smaller group meetings (of those charged with coding the qualitative date), the project identified and solved numerous problems with the current scheme. A plan was developed to divide and assign the transcription work, and the need for additional coders was identified (see Addendum 1a above). It became clear upon close inspection of our aims and a sample of interview transcripts, that the coding scheme needed additional codes and refinement of existing codes to code the range of responses and experiences captured in data collection. Further, we identified "quality of life" (aim #2) as the central issue to guide our initial data analysis, to be followed by "bladder and bowel complications" (aim #1).

The refined coding scheme was tested by having four members of the study team code the same transcript and bring results together for discussion. Refinements were made based on these tests. The final coding scheme reflects not only increased specificity of the issues we're attempting to capture and better understand, but a higher degree of efficiency by virtue of the use of fewer codes that, in combination, capture a more-nuanced sense of our data. Coding began in earnest during Month 23 and has proceeded quickly (see below for discussion of coding implementation and progress).

3. **Recruitment related tasks**
Tasks include development of a plan for recruitment to include all sites with special attention given to the VA and MPVA. The U-M SCIMS database will serve as another source of recruitment as will our SCI Registry and community-based agencies. (Months 5-30)

3a. Send letters of invitation, phone contacts, informed consents and conduct eligibility verification with participants; scheduling interviews and focus groups (Months 6-25)
This activity was successfully begun during Year 1 (as reported in previous Annual Report).

Year 2 Activities:
Recruitment continued during Year 2 to identify and approach potential participants. Recruitment for U-M participants was successfully completed for all cells. See Table 1. VA recruitment is 80% completed. There were no females recruited from the VA. Of those recruited for the VA 90% has paraplegia and 70% tetraplegia. Use of recruitment databases, advertising through approved flyers, and referrals from physicians and advisory council members greatly assisted in our recruitment. Study Coordinator Rohn attended an open house at MPVA (Month 19) and was able to recruit several additional participants. Upon receiving information about these participants, they were individually contacted, screened for eligibility, and consented into the study. Individual interviews were scheduled accordingly. Participants whose caregivers were interested in participating in this study were also contacted with approval from SCI participants. Please refer to Tables 1-3 in the Supporting Data section for a more detailed breakdown of our recruitment efforts. Recruitment will continue until all subjects are recruited, enrolled and interviewed or until the first quarter of Year 3, as planned. U-M caregivers recruitment has been complete while 60% of caregivers have been recruited from the VA.

3b. Organize interview schedules and focus group activities with the sites (Months 6-25)
Interviews were scheduled between the participant and staff member(s) assigned to interview them. This process is working well and allows the staff and participants flexibility in making and keeping appointments. Focus group planning has not yet begun and is scheduled for the beginning of the third year. Interviews are scheduled to continue until the second quarter of Year 3 as necessary. There are currently 4 veterans with SCI and 4 veteran caregivers left to be interviewed before data collection is complete for this phase, leaving only focus groups to complete. Because we already completed UM interviews, we do not anticipate any delays in scheduling focus group interviews next once VA interviews are done. Sunny Roller MA is completing caregivers' interviews. Focus groups planning will start as soon as all interviews are completed.

4. Data collection and data processing tasks
Tasks include conducting interviews/focus groups with the 80 participants (persons with SCI and caregivers); conducting focus groups; processing qualitative and quantitative data and data entry (Months 6-33). Fifty-two individual interviews have been conducted out of 60 (86%). An additional 20 individuals will participate in focus groups. All interviews in the U-M arm of the study are complete. A total of 45 (75%) individual interviews were completed in Year 2.

4a. Train interviewers, conduct individual interviews, administer measures (Months 6-30)
Training was conducted in Year 1. For Year 2, interviewing and administering measures is nearing completion, with the exception of 4 VA SCI interviews and 4 VA Caregiver interviews.

4b. Have SCI participants complete 2-week Bowel and Bladder Diaries and Summaries (Months 6-31).
This activity was dropped as it was felt that it would duplicate work being done already by the UM SCI Model System program. This was discussed in a letter to the sponsor addressing reviewers concerns.

4c. Enter data based on subject diaries into SPSS database (Months 7-32)
N.A. See information above.

4c. Conduct two focus group interviews, with SCI and caregiver groups (Months 25-30)
Planning for focus groups will begin soon (Month 25). Focus groups are to be conducted in Spring 2015 (Month 30).

4d. Mail audio files to the transcription services (Months 9-31)
All completed transcripts (n=45) during Year 2 have been checked for accuracy and cleaned of all remaining identifying information on an on-going basis. Transcripts are loaded into NVivo 10 for coding.

4f. Have focus group audio files transcribed, enter narratives into NVivo database and code interviews (Months 22-33)
Focus groups are not scheduled to take place until the end of the second year or early in Year 3. Transcription will be completed following completion of the focus groups. We will delay starting focus groups until Spring of 2015 when the weather improves in Michigan. Winter weather makes travelling for those in wheelchairs very difficult. Focus groups will be transcribed and entered into NVivo 10 for coding. The relevant coding scheme (SCI or caregiver) will be applied to the focus group transcripts. New codes to capture group dynamics, if necessary, will be developed and implemented by study team members.

Year 2 Activities:
Coding implementation and progress (Months 23-30)
Following refinement of the coding scheme and hiring two new coders (Zafiroff and Madrid), coding training and quality insurance procedures were implemented. Inter-rater reliability among coders was completed following a practice and training session to ensure adequate coding standards. The proposed tree node application structure for coding is contained in the original grant application in the project narrative (Figure 2), as was refined as discussed above. Quantitative measures are scored on an on-going basis, and will be entered into SPSS in the near future, when more data is available and data analysis is set to begin.

Coding has proceeded ahead of schedule. As of this report, 28 transcripts of SCI interviews have been completely coded (out of 36 available transcripts). Coding of caregiver interviews will proceed following completion of available SCI interviews. Refinement to the current coding scheme may be necessary to address the differences in caregiver interviews. Zafiroff and Study Coordinator Rohn will test the current SCI coding scheme on a sample of caregiver interviews to determine what changes are necessary. This coding scheme will also be subject to careful inter-rater reliability checks in the same way as the current coding scheme.

5. Data analysis and evaluation tasks
Tasks include mixed method analysis and triangulation of data. Includes evaluation of activities related to the conduct of the investigation itself (Months 11-35).

5a. Prepare basic statistics to describe samples and their scores; perform statistical analysis and qualitative analysis of transcripts for themes and patterns (Months 11-34)
These data analysis tasks are being organized by Mr. Forchheimer. A RedCap database has been developed to include data from all the questionnaires and participants' demographics. Early reviews of the data collected so far were conducted for quality control to ensure accuracy,

look for outliers and missing information. Formal analysis of the quantitative data is planned following the completion of all individual interviews (by Month 30). Qualitative analysis for themes and patterns in the interview transcripts will begin in the first quarter of Year 3, following completion of coding.

5b. Conduct triangulation of qualitative and quantitative data sets (Months 15-34)
An initial meeting took place in November 2013 (Month 14) with project investigators, consultants and staff members who have experience and expertise in mixed method analysis to begin planning for this data analysis task. Triangulation was discussed in terms of a data analysis approach to be undertaken once data entry is completed. Subsequent meetings among investigators, research staff and consultants continued the discussion of triangulation of data. Formal plans for triangulation are in progress and will be implemented.

During the course of revising our coding scheme, we further discussed how we would begin integrating qualitative and quantitative datasets. In Month 18, Dr. Lequerica gave a lecture on the topic of mixed methods in research and examples of how to best integrate our data using these two methodological approaches. The approach suggested was discussed with study coordinator, Martin Forchheimer MPP, responsible for the integration of the quantitative data.

This meeting helped us to identify the seminal literature on mixed methodology that has greatly assisted us in planning the next stage of our analysis. As coding continues, we will begin to process the quantitative data. Once both coding and statistical analyses are complete, we will return to integrate both datasets more intensely, looking to test and possibly confirm findings from one dataset by virtue of the other. We will return to this task beginning in Month 30.

5c. Review data regularly to evaluate coding schemes, discuss patterns emerging, and findings from the quantitative analysis (Months 13-33)
Team members have already begun discussing preliminary patterns that seem to be emerging from the limited current data set. This was done to determine that the qualitative interviews are capturing the necessary quality of life information we require to address our aims. As more data is collected, this research task will become more involved. Regular meetings between staff members and consultants continue to take place to maintain a unified sense of purpose moving forward. Dr. Duggan continues to play an important role in providing guidance to this process.

5d. Review focus group data and integrate it with other qualitative data (Months 20-33)
As focus groups have not yet been conducted, this task is yet not completed. Planning has begun and focus groups will take place during Months 30-33.

5e. Analyze data from the Bowel and Bladder Diaries, including conduct of linear mixed models (Months 24-34).
N.A. as detailed above.

5f. Conduct regular meetings to discuss data interpretation and evaluation (Months 11-35)
The entire project team meets quarterly for updates and to roll-out and reinforce procedures. These meetings have included reports on recent collection – including brief outlines of informal findings from individual interviews. Further, the PI and study coordinator meet weekly, alone and with interview staff, to discuss progress on the data collection and interviewers initial impressions of the type and quality of data being collected.. The study coordinator also met with other SCI staff to discuss recruitment through SCI clinics and SCI Registry and data management on a regular basis. As data analysis becomes the focus of the project for Year 3,

regular meetings with Mr. Forchheimer and consultants Lequerica and Duggan will continue to occur.

6. Dissemination and data sharing tasks

Tasks include discussions with focus groups at U-M, VA and MPVA, presentations at the MPVA and national meetings, website links to project activities, products and findings. We will use the existing U-M SCIMS website with links to the VA and MPVA sites to distribute this information. (Months 10-36).

6a. Appointment of a DSMB and development of a data sharing plan (Months 5-10)
The project does not require a DSMB.

6b. Development and dissemination of findings in lay language to persons with SCI, their families and caregivers through a second presentation at the AACIL and MPVA, consumer brochures and fact sheets. These will be distributed through websites, presentations and meetings (Months 25-35).
As this is planned following the completion of data collection and analysis, this task has not yet begun. Relationship with MPVA is in place and they are eager for us to present. As part of our recruitment efforts, Study Coordinator Rohn has met with and discussed initial findings with potential participants at MPVA.

6c. Presentations at DoD and CDMRP sponsored meetings (Months 11-36)
NA – as these have not yet occurred. Year 2 has focused on data collection and beginning of data analysis instead.

6d. Preparation of final report and manuscripts (Months 15-36)
At the beginning of Year 2, two poster presentations were made at the 52nd annual meeting of the International Society of Spinal Cord by the PI (October 2013). These presentations used preliminary data only. Abstracts were published in the conference book. The first presentation was entitled: Development of Interview Forms for the International Spinal Cord Injury Datasets for Bowel and Bladder (Tate, Forchheimer, Chiodo, Rodriguez, Pelletier Cameron, Hartwig, and Pines (2013). The second poster presentation was entitled: The Effects of Bowel and Bladder Dysfunction on Quality of Life after SCI (Tate, Forchheimer, Roth, Nevedal, Rodriguez, Pelletier-Cameron, Chiodo, Kalpakjian and Meade). While the first presentation showed the development of the Bowel and Bladder Treatment Inventory (BBTI) being used in this study; the second illustrated the qualitative methodology being used here and in a previous study of women with SCI. Five cases were presented from this study and discussed.

Final report will be prepared following the completion of the project. Project team members have begun strategizing potential publications, to be completed as more data is collected and analyzed. Investigators, staff, consultants and collaborators discussed a number of potential presentations.

An initial publication by Rohn, Tate, and Forchheimer will focus on conceptualizations of the effects of neurogenic bladder and bowel on QOL by our study population. This will be a foundational paper to help contextualize the more complex work to come. It will identify and describe the various themes and patterns across our sample in regards to QOL.

A second publication by Nevedal, Kratz, Rohn and Tate will describe specific cases of persons of SCI and caregivers. These case studies will focus on the change over time of a subset of our population who also participated in an early women-specific study on SCI QOL. This study will deepen the work of the initial publication.

A publication on the development of the BBTI (poster presentation made in 2013) will be prepared by Tate and Forchheimer and others. Lastly, the group discussed the need for a first publication based on transcripts focusing on QOL outcomes. The first two publications will be prepared and submitted early in 2015 to be followed by the third in Spring of 2015.

Key Research Accomplishments

- We have completed the data collection (100%) process for the U-M site (see Tables 1-3) and 86% of all data collection related to individual interviews.

- A coding manual for SCI participants has been developed, refined and implemented for the project.

- Two new coders (Zafiroff and Madrid) were hired and trained.

- Coding is proceeding at greater-than-anticipated pace and formal analysis can begin soon. Of SCI participants interviews transcripts, 28 have been coded so far.

Reportable Outcomes

Year 2 activities focused on completing our data collection and beginning coding of SCI interviews. Abstracts were not submitted during this year of the grant as we wanted to complete our data collection first. We have begun to review our data to scan for potential differences between the two cohorts: civilians and military.

Conclusion

We have completed 30 interviews from the U-M site and 26 from the VA site. We are very pleased with our progress so far in spite of initial difficulties with recruitment and scheduling appointments. We also believe that our methodology to conduct such mixed model projects can be an example for other projects alike and we plan to write it up as a publication. The participations of the Ann Arbor VA and Michigan Paralyzed Veterans Association have been key to our success in recruiting participants for this project. Year 3 will focus on conducting our focus groups and data analyses. We are eager to begin writing manuscripts, as well as begin presenting our results.

Supporting Data

Table 1

SCI Recruitment and Data Collection by Overall Neurologic Level of Injury					
Sample Arm	Neuro Level	Identified	Screened	Completed	% Complete by Neuro Lvl
UM SCI >10 years (N=10)	Para (N=5)	8	8	5	100%
	Quad (N=5)	9	9	5	100%
UM SCI <1year (N=10)	Para (N=5)	22	8	4	100%
	Quad (N=5)	22	9	6	100%
VA SCI Long (N=20)	Para (N=10)	12	12	9	90%
	Quad (N=10)	13	12	7	70%

Table 2

SCI Recruitment and Data Collection by Sex					
Sample Arm	Sex	Identified	Screened	Completed	% Complete by Sex
UM SCI >10 years (N=10)	Male (N=7)	11	11	6	100%
	Female (N=3)	6	6	4	100%
UM SCI <1year (N=10)	Male (N=7)	20	10	6	100%
	Female (N=3)	24	7	4	100%
VA SCI Long (N=20)	Male (N=20)	25	24	16	80%
	Female (N=0)	0	0	0	0%

Table 3

Caregiver Recruitment and Data Collection by Research Site					
Sample Arm	Site	Identified	Screened	Completed	% Complete
Caregivers (N=20)	UM (N=10)	20	11	10	100%
	VA (N=10)	10	10	6	60%

Psychosocial and Behavioral Factors Associated with Bowel and Bladder Management after SCI
SC110228
W81XWH-12-1-0524

**PI:** Denise Tate, PhD   **Org:** Regents of the University of Michigan   **Award Amount:** $614,110

Study/Product Aim(s)

• To identify risks associated with neurogenic bladder and bowel complications after SCI.

• To determine the influence of these complications on quality of life.

Approach

The sample consists of 60 persons (40 subjects with SCI and 20 caregivers). The project uses a mixed method approach with both a qualitative and quantitative components. Issues around quality of life for those with neurogenic bladder and bowel are the key focus, as are differences between veteran and civilian participants. Data collection is on-going and preliminary data analysis has begun.
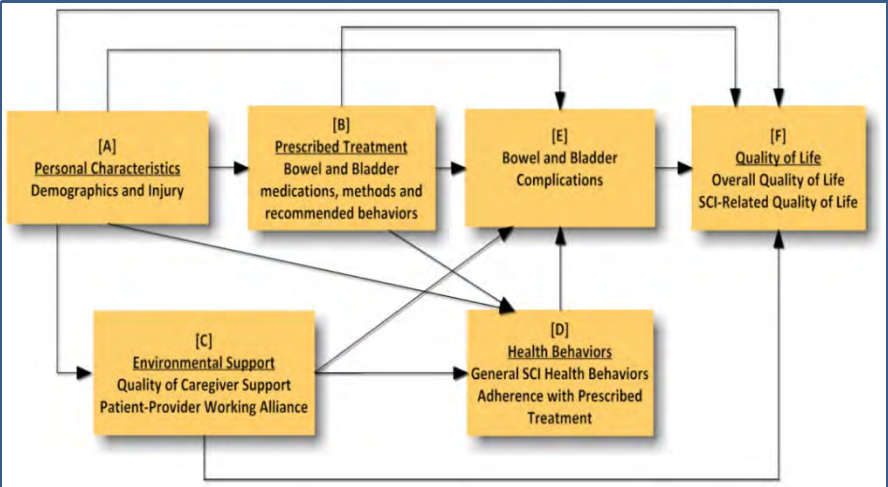
Project is on target in terms of data collection. Coding and analysis has begun with an eye towards dissemination and first publications beginning in the third quarter 2014.

Timeline and Cost

Activities Project Year*	Y1	Y2	Y3
Administrative start-up (IRB, staff, equip)	▉		
Research Design (surveys, databases)	▉		
Recruitment (registry, flyers, referrals)		▉	
Data collection and processing		▉	
Data analysis		▉	
Dissemination and data sharing		▉	
Estimated Budget ($K)	**$57K**	**$215K**	**$342K**

*Y1: 10/1/12 – 9/30/13; Y2: 10/1/13 – 9/30/14; Y3: 10/1/14 – 9/30/15

Goals/Milestones:

Y01 Goals – Administrative start-up
☑ IRB and other regulatory approvals established and approved
☑ Staff hired and trained; consultant agreements finalized
☑ Equipment, data analysis software, and supplies acquired
☑ Research instruments and databases piloted, refined, and finalized

Y01-Y02 Goals – Data collection
☑ IRB-approved recruitment strategies formalized and implemented
☑ Data collection and processing begun and ongoing

Y02-Y03 Goals – Data analysis and dissemination
☐ Completion of data collection and processing (transcription)
☐ Apply statistical analysis and interview coding schemas
☐ Disseminate findings: funding agency, peer-reviewed journals, etc.

Comments/Challenges/Issues/Concerns
Project has increased enrollment and is on target for finishing data collection. Interview transcription is keeping pace with data analysis. Data analysis has begun and publications are in the planning stages.

Budget Expenditure to Date
Projected Expenditure: $229, 396
Actual Expenditure: $218,568

Updated: October 29, 2014

DoD Project
Coding Scheme:

Persons with SCI

Quality of Life:
QOL Reflections
Subjective QOL Rating

General Codes:
Aging
Bladder
Bowel
Caregiver
Good Quote
Not sure
Sexuality
Veteran

Physical Factors:
Health Conditions
Health Behaviors

Psychological Factors:
Emotional State
Stress Appraisal
Coping Strategy

Social Factors:
Social Role Private
Social Role Public
Social Support

Environmental Factors:
Physical Environment
Community Resources
Financial Resources

Personal Factors:
Demographics
SCI Experience

CODING MANUAL

Coding Scheme & Instructions 1:
Persons with SCI

For the Department of Defense Study:

*Psychosocial and Behavioral Factors Associated
with Bowel and Bladder Management after SCI*

CODING SCHEME

1. **ENVIRONMENTAL FACTORS**
   a. **Community Resources**
   b. **Financial Resources**
   c. **Physical Environment**

2. **GENERAL CODES**
   a. **Aging**
   b. **Bladder**
   c. **Bowel**
   d. **Caregiver**
   e. **Sexuality**
   f. **Good Quote**
   g. **Veteran**

3. **PERSONAL FACTORS**
   a. **Demographics**
   b. **SCI Experience**

4. **PHYSICAL FACTORS**
   a. **Health Conditions**
   b. **Health Behaviors**

5. **PSYCHOLOGICAL FACTORS**
   a. **Emotional State**
   b. **Stress Appraisal**
   c. **Coping Strategy**

6. **QUALITY OF LIFE**
   a. **QOL Reflections**
   b. **Subjective QOL Rating**

7. **SOCIAL FACTORS**
   a. **Social Role Private**
   b. **Social Role Public**
   c. **Social Support**

DIRECTIONS: The following code indexing guide is intended to facilitate the coding of narrative text from transcribed interviews. As needed, definitions and / or descriptions are provided. For some coding categories, examples are included to make the coding scheme clearer in its application. Multiple codes can be assigned to any given line or lines of text, as appropriate.

ENVIRONMENTAL FACTORS: COMMUNITY RESOURCES

Definition:

The *social* environment refers specifically to the informal and formal social arrangements through which people conduct their daily life activities. Refers to community agencies/or groups such as

Components:

a. <u>Medical & health-related goods and services</u>: including goods and services provided by primary care physicians, specialists including PM&R, health care providers, and payors (insurance), case-managers, durable medical equipment and supplies, nursing services, personal care attendant services, and peer support groups, etc.

b. <u>Community services</u>: including public, commercial and or private transportation services, social services, law enforcement and legal services, and any other public or private goods and services and goods that are not health-related (e.g. restaurants, retail establishments,

Common locations:

Examples:

"The biggest problem that comes up almost all the time is dealing with insurance…   the stuff they put you through. You have to get re-certified every week and it just puts so much tension in the air on everybody with the staff here and I don't know why they can't do two-week acceptances at a time. It's kind of crazy that they have to re-certify every week, whether or not I'm making progress. As soon as you stop making progress then the insurance company wants to sweep you out the door…they're just ruthless…. But there's a lot of people involved with… like they'll hit a hiccup here and there and then the other people get involved trying to straighten out the hiccup and dealing with insurance companies is like trying to [herd calves] Can't get the same answer twice in a row from anybody…Yeah, you're getting bills every week for something. When they come and draw blood from you, you can expect another two or three bills. Stuff that should have been sent to the insurance company, they're sending it right to your door. Now you gotta do their job and the insurance company's" (UM-040).

"…just because I have 24-hour nursing, I have the flexibility to go where I want when I want. I have somebody to help me empty my bladder wherever I'm at whenever I need to. It doesn't limit me. If I did not have 24-hour nursing, if I had to have an indwelling catheter or try and plan around people coming and emptying my bladder, life would just be so much more different and restrictive" (UM-020).

"Well you know if I'm going to work I know which bathroom is accessible, easily accessible, has everything I need to use. If you're going out to a restaurant you never know what the restaurant restroom bathrooms are going to be situated like or if you're traveling for business or another facility, you never know what it's going to be like. Sometimes it gets like, you can't shut the door, or you can't even get into the stall. It depends on how the ADA, how generous they were when they set up the building" (VA-002).

ENVIRONMENTAL FACTORS: FINANCIAL RESOURCES

Definition:
        Includes the following personal income and assets, and monetary resources from health and auto insurance etc.

Components:
1. Personal income from work:
2. Insurance payments – health and auto:

Common locations:

Examples:
        "I'm on short-term disability which will probably turn into long-term disability before long….I turned 61 so I could just go on Social Security as disabled which I guess for me wouldn't be a bad deal. Along with my retirement benefits and stuff I'd do pretty well….Yeah, if I could just retire and go on Social Security and get the benefits I need to exist on I'd just be fine with that" (UM-040).

        "I lived in Michigan. I owned a house in Michigan that was modified. It was beautiful. It was on the water….now I'm in El Paso, Texas. I just have bought a house and we're in the middle of remodeling to make it accessible for me, but overall, life is really good…Allstate offered to pay for my master's [MSU] to go back to school…. and the doctorate was there. Michigan State was waiting for me when I was ready and that was paid for. I had to do a TA and a GA and I didn't make a lot of money, but it was enough to survive" (UM-020).

        "I planned on being a career military guy and now I'm data geek at a billion dollar company so, a little different. I still don't know what I want to be when I grow up. I know that I will still be working; I have a four year old and a nine year old. So retirement's at least 14, 15 years away so I'll still be working. We've thought about opening our own business or something so we can work together instead of me driving an hour away, but don't know" (VA-002).

ENVIRONMENTAL FACTORS: PHYSICAL ENVIRONMENT

Definition:

The *physical* environment refers to specifically to the natural environment and the man-made environment (or built) environment. Statements reflecting facilitators or detractors should be coded at this node.

Components:

1. <u>Natural environment</u>: such geography, climate, weather conditions such as snow rain, and temperature.
2. <u>Man-made environment</u>: such as residential dwelling units and surroundings, commercial, civic, and religious structures and surroundings, transportation systems etc.

Common locations:

Examples:

"Yeah, there's a lot of things….like in my room here I got a refrigerator that's on the floor under a cabinet – so if I roll up to it and try to open it, I have to roll up to it sideways to open it and then I have to get out of the way of the door…so I can see what's in it. And then I have to turn around and get as close as I can side-to-side on it so I can reach in and get what I want so that's rather difficult. And a lot of things get placed just out of my reach" (UM-040).

"My old office had a bathroom….Now what we do is we in my office and then we either empty the urine into a bottle or they just take the bag into the bathroom, empty it and come back and put it back on the back of my chair.

"It's a bitch to fly, yeah. You've got to transfer out of your chair into one of those chairs that they take you onto the plane and then they have to transfer you from that to the airplane seat and back and forth and back and forth. That will break your chair. Being in El Paso, there are almost no direct flights anywhere. We transfer twice. I have to rent a Hoyer and it's not an electric Hoyer, it's a hydraulic Hoyer, and I have to rent a van so I have to tie down in that lockdown…I would go where there was a McDonald's because I knew McDonald's were guaranteed to have a bathroom that was big enough that I could recline and cath" (UM-020).

"…like when they moved me from the Flint office to the Detroit office I made sure that there was a restroom that was accessible and when they brought me down they told me that if there was anything I needed at the restroom they would modify it, but I didn't actually need it luckily... I don't go someplace because I know that they have sand, I avoid those. Wheelchairs and powdered sugar sand don't go well together, stuff like that or that place is too hilly or what-not….If you're going out to a restaurant you never know what the restaurant restroom bathrooms are going to be situated like or if you're traveling for business or another facility, you never know what it's going to be like. Sometimes it gets like, you can't shut the door, or you can't even get into the stall. It depends on how the ADA, how generous they were when they set up the building…My folks when they rebuilt their house made sure they built a special bathroom just for me" (VA-002).

GENERAL CODES: AGING

Definition:

      Any talk of aging, getting older, or physical changes over time in the body, whether or not it is related to SCI or other health conditions or complications.

Components:

1. Related to just getting older
2. Related to health changes from getting older

Common locations:

Examples:

GENERAL CODES: BLADDER

Definition:
Any talk or description of the individual's bladder. This can include general reflections, health complications, management, bladder program, etc. In general, this is a code that will help us identify talk around bladder and will often be paired with another code.

Components:
3. <u>Bladder talk</u> – general reflections and the like around their bladder.
4. <u>Bladder health concerns</u> – talk around the medical aspects of neurogenic bladder.
5. <u>Bladder management</u> – talk around the bladder program, supplies, & health behaviors.
6. <u>Bladder problems</u> – talk around how bladder issues interfere with quality of life.
7. Examples: Talk about self cathing, laying down, menstruation and cathing, need a bed to cath. Finding place to cath, self cathing, pain.
8. Key words: bladder, UTI, cath, indwelling cath, intermittent cath, accidents, diapers, pads, bottle, leg bag, suprapubic tube

Common locations:
- SECTION 1: BACKGROUND INFORMATION, Question 2
- SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
- SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

Examples:
"Yeah. It's interesting because I've heard some research that says that given the choice of walking or having your bowel and bladder restored people would actually choose bowel and bladder. To me, it is problematic. It's something that I've learned to live with and accommodate, but it's certainly one of the top five issues that we have to deal with as an individual with a spinal cord injury. Generally, I'm continent, and I hate to say that because I don't know that I've been incontinent in six or eight months, but as soon as I say that I'm continent, something happens and I have a problem" (UM-020).

"My story of living without bladder and bowel function, I can tell you right now when I was first injured it was actually quite a shock. When you hear about people being paralyzed you don't realize, well they can't walk, but you don't think about all the things that come along with it, bowel, bladder, skin care, all that good, fun stuff. It was very enlightening, let's put it that way. But I developed a routine, it's worked well for the bowel. On the bowel side of things it's, luckily I don't have a whole lot of digestive problems, so it's pretty, you know once a day standard routine, it's no big deal. But the bladder, that's a pain in the backside because you got to find a restroom where you can do the intermittent catheterization, you got to find a place, you got to find a bathroom that you can use, you got to carry all this stuff around with you to do it. Then you're always worried, well I am, I don't know about other people, but if I start coughing or laughing I might you know have a leakage. Then you have the UTI's that come along with that" (VA-002).

GENERAL CODES: BOWEL

Definition:

Any talk or description of the individual's bowel. This can include general reflections, health complications, management, bowel program, etc. In general, this is a code that will help us identify talk around bowel and will often be paired with another code.

Components:
1. Bowel talk – general reflections and the like around their bowel.
2. Bowel health concerns – talk around the medical aspects of neurogenic bowel.
3. Bowel management – talk around the bowel program, supplies, and health behaviors.
4. Bowel problems – talk around how bowel issues interfere with quality of life.
5. Key words: digital stimulation, bowel, colostomy, commode chair, accidents, diapers, pads, suppository, constipation, diarrhea

Common locations:
- SECTION 1: BACKGROUND INFORMATION, Question 2
- SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
- SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

Examples:

"The bowel program is every other night. Every other day in the evening during 9:00. Throughout the years I've had problems with the sluggish bowel, et cetera, and for years my nurses have been telling me, "Why don't we try the warm prune juice at night?" Finally, I agreed and that was about two months ago and that has really changed the quality of my bowel program. It's really made a huge difference" (UM-020).

"Yeah, bowel care, every morning I basically do digital extraction, and that's pretty much it. I don't use any suppositories or anything like that. And so far it's been pretty good. I mean not a whole lot of issues there unless you get the flu, and that's never good. Bladder, I catheterize four times a day, more if I am drinking heavily, but typically four times a day. I wear an external catheter and a leg bag for leakages which works out fine unless you're coughing really hard, and then you have incidences of leakage and whatnot" (VA-002).

GENERAL CODES: CAREGIVER

Definition:
      Any talk or description of the individual's caregiver. This is a code that will help us identify talk around caregivers and caregiving will often be paired with another code. This code will help us zero in on reflections and experiences with caregivers and caregiving.

Components:
1. <u>Caregiver</u> – any mention of the participant's caregiver.
2. <u>Caregiving</u> – any mention of assistance the participant receives related to their SCI or bladder/bowel.

Common locations:
- SECTION 1: Background information
- SECTION 2: Bowel and Bladder Program
- SECTION 3: Caregiver/Attendant Relationship
- SECTION 4: Social Relationships, throughout

Examples:
      "Over the 15 years, 95% of the nurses have been absolutely fabulous—trustworthy, hardworking, honest, have integrity. I manage my own nursing case, so I hire them. That has made a huge difference" (UM-020).

      "Yep, they're all doing their jobs and none of them are griping and they're more than willing to help me out with anything I need. If I need something from my room that's out of reach, they'll come and get it for me with no problem" (UM-040).

      [Referring to wife as caregiver] "Not anymore, initially she would help me out until I developed strategies or figured out how to do it on my own, but that's been I don't even know how many years now. Same with the bowel program, when I first started, she'd be there helping me, and then I figured out strategies so I could do it independently. Now if for some reason I have a loose, loose stool where it's rather messy, she will come in and help me and make sure I don't spread it over the rest of the house. Yeah, if I need her she comes in and helps out with that stuff, but for the most part, on the average day, she does not get involved" (VA-002).

GENERAL CODES: GOOD QUOTE

Definition:

Any talk or response from the participant that is particularly noteworthy, well summarizes the data either within the interview or as an exemplar of broader patterns in the entire dataset, or is particularly poignant and sets this individual statement apart from others. These quotes should be labeled with publications in mind, in that they help demonstrate the specific aims of the project or other key topics to capture around NBB and SCI.

Components:
1. Quotes should be identified as important and particularly poignant for the study.
2. Quotes should be coded in a broad way to include context of quote.

Common locations:
- Potentially throughout.

Examples:
1. (Copy and paste quotes from transcripts)
2. (Add 2-3 examples)

GENERAL CODES: SEXUALITY

Definition:

Any talk, descriptions, or perceptions of sexuality, sexual intimacy, sexual behavior or orientation. This code will help us identify the meaning of sexuality to the participant and may help us determine how sexuality is impacted by neurogenic bladder and bowel.

Components:

1. <u>Sexuality</u>: general perceptions of sexuality, changes since SCI, talk about desires for or avoidance of sexuality
2. <u>Sexual behavior</u>: any mention of physical dimensions of sexuality, barriers to sexual activity, ways sexuality changed since SCI or NBB
3. <u>Physical functioning</u>: ability to engage in sexual behaviors after SCI
4. <u>Sexual intimacy</u>: any mention of sexual relationships, spouse, partner (past or present), dating, discussions of how intimacy has changed since SCI or NBB
5. <u>Sexuality and relationship to caregiver</u>: caregivers may be spouses/partners, identify talk about challenges between caregiver role and romantic partner role
6. Other topics/keywords may include: romance, love, dating, kissing, intercourse, touch

Common locations:

- SECTION 4: Sexuality, social relationships

Examples:

"I was married when I had my injury and since then I have not have any relationships or really thought out any relationship with a man. It's interesting, though. It's hard to say if the spinal cord injury is impacting that because most of my life I've been fairly independent. I've always been working and in school so I've always put relationships on hold because of the other goals that are in my path. I have to say right now I barely have time for friends. I know I don't have time for a relationship. Do I see myself probably five years from now actually making an effort and seeking that out? I'd say yeah, probably, but I've got to be honest and say I think it's going to be difficult. I think it's going to take a certain man, a certain individual to see past the spinal cord injury in order to have a relationship. I don't know. We'll see how that goes. My self-esteem is high. I value myself as a person. I think I'm lovable. I think that if I invest the time, that I will find somebody out there that will love me and we can have a relationship together. But like I said, right now I haven't made it a priority. I'd have to say maybe 30% I'd attribute to spinal cord injury and 70% I would attribute to just too damn busy for a relationship, honestly" UM-020.

"Definitely with the bladder, you have to worry about passing UTI's and all that good stuff. When I was using a Foley when I was first injured you have that whole ugly thing in the way, so that definitely impacts it. It was much more mechanical, more scientific than natural, how's that?" (VA-002)

GENERAL CODES: VETERAN

Definition:

Any talk of military service or veteran status.

Components:

Common locations:

Examples:

PERSONAL FACTORS: DEMOGRAPHICS

Definition:

Demographics will include basic socioeconomic and injury background information about the participant.

Components:

Education, age, gender, injury level, research site (UM/VA), time since injury, caregiver (y/n), bladder/bowel program type.

Common locations:

- This information will not be content coded in NVivo. This information will be in SPSS/EXCEL. We will create attributes for participants and import the demographic information into NVivo.

Examples: n/a

PERSONAL FACTORS: SCI INJURY EXPERIENCE

Definition:

This code will be used to identify talk about the SCI injury experience

Components:

- Details about the SCI injury (cause, timing in life)

Common locations:

- This is discussed in the first question of the interview ("tell me the circumstances surrounding your injury")

Examples:

"I was injured on December 3rd of 1997 in a motor vehicle rollover accident. I did my rehab at the University of Michigan Model Spinal Cord Injuries care system. At that time, I had my bachelors in business. Because it was an auto accident, I had a lot of resources and was able to go back to school for my master's, which I started in probably about 2000." (UM-20)

"Yeah, I've always been heavy into the outdoors and when I was a young child I even did some lumberjack work – I was 13 or so. Anyway, I've been around trees all my life – cutting them and stuff and I was trimming a branch in my yard and I had a ladder chained to the tree and I had the [inaudible 0:00:58] tied to the tree and then while I was cutting the tree, the tree… the big limb starts splitting the main trunk. When that happened it broke the chain and when it broke the chain, the chain slidded and it grabbed the ladder and pulled the ladder to the side and it dumped me out of the tree. I landed on my back from about 16 feet up and I broke my back and crushed my spinal cord and broke three ribs on one side and another rib on the other side so I was pretty beat up." (UM-40)

PHYSICAL FACTORS: HEALTH BEHAVIORS

Definition:

Any description of the individual's actions in managing their own health and wellness, including reducing symptoms, alternative therapies, seeking medical advice, etc. Behaviors taken to treat their neurogenic bladder and/or bowel, past or present, is key. Any description of the individual's actions in terms of addressing or responding to their own health. Focus is on behaviors, conscious or unconscious, that contribute to participant's health and wellness; personal agency managing illness and disease – NBB and managing related complications rather than physical symptoms or the complications themselves (use Health Conditions for this). Further, this is not emotional or psychological coping with NBB (use appropriate Psychological Factor codes for this), but rather actions used in management. Code these management strategies whether the strategy is current or no longer used, significant or minor. These can include personal techniques or daily strategies, physician-recommended or ordered approaches, non-medical treatments, over-the-counter remedies, holistic medicine.

Components:
1. Bladder management: includes description of bladder program, use of catheters, decisions of when and how to cath, routines, strategies for preventing or responding to accidents.
2. Bowel management: includes description of bowel program, materials used for bowel program, routines, and strategies for preventing or responding to accidents.
3. Illness management: includes strategies and recommendations for managing or treating other diseases or illnesses
4. Recommendations: includes recommended courses of action/treatment from physicians or other sources.

Common locations:
1. SECTION 1: BACKGROUND INFORMATION, Question 2
2. SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
3. SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions
4. SECTION 3: RELATIONSHIP WITH DOCTOR/HEALTH CARE PROVIDERS, all questions

Examples:

"But generally, both my bladder and bowel are very, very stable so I really don't have issues. I do have 24-hour nursing, so I have a nurse that travels with me and I do intermittent catheterization every two to three hours as needed, and then the bowel program every other night" (UM-020).

"But it was there all the time and they would change me from a leg bag to a night bag when I went to bed at night. And my volumes have been fairly high I guess as far as that goes but trying to get me to drink less fluids and also trying to get me to lose some weight so that I can handle my weight a little better as far as transfers to" (UM-040).

PHYSICAL FACTORS: HEALTH CONDITIONS

Definition:

Any description of the individual's medical or health-related conditions, diseases, diagnoses, complications, etc. These can be related to or resulting from neurogenic bladder and/or bowel, past or present, but should be double-coded with "bladder" or "bowel" as appropriate. Focus is on physical symptoms and disease rather than personal agency and health behaviors (use Health Behaviors code for this). Code whether the disease, diagnosis, or complication is current or resolved, significant, minor, or no impact. These can include personal recalled experiences (that may not include a medical label or diagnosis) or formal medical diagnoses.

Components:
1. Diseases and medical conditions: this can include bladder/bowel, injuries, comorbidities, other medical symptoms and circumstances.
2. Complications: Complications or symptoms resulting from any medical condition. For NBB this includes UTIs, kidney or bladder stones/infections, leakage, incontinence, pain related to urinary system or urinating, sores from cathing. Hemorrhoids, constipation, incontinence, bloating, pain related to bowels or having a bowel movement, skin infections, sores.

Common locations:
1. SECTION 1: BACKGROUND INFORMATION, Question 2
2. SECTION 2: BLADDER AND BOWEL PROGRAM, all questions
3. SECTION 3: MANAGEMENT CHALLENGES & HEALTH COMPLICATIONS, all questions

Examples:

"Bowel accidents, I think in the 20 years I think I've had two. I've been very lucky on the bowel side. The bladder on the other hand, that's a constant, especially when I get allergies and start sneezing and coughing and you're always wondering, did it slip off or can anybody smell that? Yeah" (VA-002).

PSYCHOLOGICAL FACTORS: COPING STRATEGY

Definition:

      Refers to a cognitive, emotional, and/or behavioral effort directed at managing, reducing, or tolerating the internal and/or external demands of life. The coping effort may or may not be successful and in some cases may have negative effects (e.g. drinking alcohol to manage anxiety). The individual may be more or less aware of using a particular strategy for dealing with a stressor or life circumstance. Coping strategies are not mutually exclusive, although an individual may rely more heavily on a particular style of coping. General or global references to coping or needing to cope that cannot be coded in accordance with the specific categories below should be coded at the parent node.

Components:

1. Emotion-Focused: Attempts to cope that are either directly or indirectly focused on managing, manipulating, and/or regulating one's emotional experience in life. Such coping efforts may include strongly cognitive or behavioral elements despite the emphasis on emotional experience. This would include attempts to view an event in a new light such as by "looking for the silver lining" or making comparisons about how "things could be worse." Other examples of emotion-focused coping include: directly expressing feelings to others for purposes of emotion-processing, withdrawing from others to avoid certain feeling states, avoiding talking about feelings, suppressing thinking about a situation or alternatively trying to think it through in order to feel differently about it, engaging in wishful thinking, daydreaming or fantasizing, using sedatives (food, medicine, or alcohol), distracting the self or otherwise achieving emotional distance from a situation such as through intellectual denial or emotional detachment, looking for the humor in life, and the use of calming or relaxation techniques.

2. Problem-Focused: Attempts to solve or somehow resolve a situation, either directly or indirectly, by initiating some type of action or intervention that is aimed at alleviating or remedying the situation. This includes chunking elements of a problem or breaking a problem down into manageable pieces, seeking information, considering alternatives, and direct action. This might also include delaying a decision or action until more information is available or suppressing action to avoid making the problem worse.

3. Social Support-Focused: Attempts to find help in coping with life or a situation by asking for advice, concrete aid, emotional support, affirmation of perceptions, positive regard of actions taken, or other form of social support. The nature of the social support sought may be either formal (e.g., attending a support group) or informal (e.g., talking with friends).

4. Meaning-Focused: Attempts to create or find meaning in one's life experience through reference to a higher being or in reference to the larger scheme of things. This includes the use of an overarching meaning system based on religious, spiritual, or philosophical beliefs and values to change one's image of nature, body, self, society, and culture. Concrete strategies include but are not limited to activities such as engaging in prayer, reading the bible, meditation, and participation in rituals. Some commonly reported coping strategies include the following: "going to church," "drawing strength from

adversity," "growing as a person," "rediscovering what is important," "feeling transformed," "taking strength from God," "finding new faith," "reading inspirational stories," "listening to faith-based programs," an so on.

Common locations:
Throughout interview.

Examples:

"I had these really humiliating moments where we would cath and I'd come out and there would be bag of urine stuck to my leg because we forgot to empty it as I flew out of the bathroom. And then I realized it can kill me, right? Life goes on. So sometimes you deal with these embarrassments and you realize that it's a part of being human and that it didn't kill you and maybe those kinds of things. Like Nietzsche says, "What doesn't kill you makes you stronger." It could have been a little bit of that, too, having to face the reality that shit happens" (UM-020)

"Beatrice Wright talked about that, shifting what's important to you and what you value, so I find other things to do at night."

"I've always been very optimistic and things that would bug people and bring them down never bothered me as much. Like the therapist said, I don't think you're going to get depressed. That's not going to do me any good, I'm still going to be, getting depressed is still going to leave me here in the chair. I don't know, I guess I just always faced life with it's what you got. You only get one shot. And make the best with whatever I got. "

PSYCHOLOGICAL FACTORS: EMOTIONAL STATE

Definition:

Any description of the individual's emotional state, past or present. Code emotional content regardless whether it is positive, negative, or neutral. Use to describe emotional states rather than psychiatric diagnoses in the cases of depression and anxiety.

Components:
1. Depression: Includes any discussion of feeling hopeless, helpless, sad/gloomy/dejected, inability to enjoy life, apathy, emotionally withdrawal, isolated/lonely(regardless of actual social environment).
2. Anger: frustration, resentment, hostility, fury, aggravation.
3. Anxiety: insecurity, vulnerability, concern, nervousness, worry, fear, terror.
4. Surprise/Shock: can range from mild surprise to disgust, horror, repulsion.
5. Stress/Overwhelmed: the emotional aspects of perceived demands exceeding personal capacity. Feeling overcome, overwhelmed, overloaded, crushed by the weight of demands.
6. Grief/Loss: sadness and grief specific to a loss event (may be linked to text that is coded as a Loss Stress Appraisal).
7. Social emotions: emotions in regard to another person or persons – embarrassment, stigma, guilt, love, hate, fondness, connection, companionship, protectiveness (as in taking care of children)
8. Happiness/Joy: positive emotions ranging from contentment/fulfillment/amusement to euphoria.
9. Optimism/Excitement/Hope: future-oriented positive emotions.
10. Gratitude: thankfulness, appreciation
11. Calm: Serenity, peacefulness, relaxed
12. Resilience/Confidence/Self-Efficacy: feelings of strength, adequacy, or of being able to "come back from" "bounce back from" or recover emotionally from difficulty.

Common locations:
Throughout the interview

Examples:

"It's funny because when I was first year post injury, we were not allowed to use the word *catheterization*. We called it *the C thing.* I was just really embarrassed. I didn't want anybody to know so it was something that I kept very hidden and very private."

"The thing is I'm happy with my life."

"I can tell you right now when I was first injured it was actually quite a shock."

"Then you're always worried, well I am, I don't know about other people, but if I start coughing or laughing I might you know have a leakage."

PSYCHOLOGICAL FACTORS: STRESS APPRAISAL

Definition:
      The perception that a situation exceeds or may exceed resources and capacity (internal or external) in terms of functioning, adaptation, or coping.

Components:
1. <u>Challenge</u>: An appraisal of an event, situation, or life circumstance that may be on the part of the individual. Challenges are more likely to be viewed as "controllable" and may be viewed as having a positive component ("good stress"). Some common challenges are associated with life transitions, such as getting married, childbirth, moving to a new locale, starting school or a new job, etc. Other challenges may be more directly related to the SCI, such as involving the carrying out of activities of daily living or arranging for transportation. Some challenges may evoke excitement or either positive or negative tone but as requiring unusual or exceptional effort eagerness, while other may evoke some degree of annoyance, anxiety, or self-doubt. Even if a challenge is perceived as exceptional and/or as having potential significant consequence for the individual, it is not viewed by the individual as posing a real or significant threat to physical or emotional well-being. In this sense, what is a challenge or threat is defined by the individual in that the same stressor might be viewed, alternately, as either a challenge or a threat depending upon personal or contextual factors.
2. <u>Threat</u>: Damage that is anticipated and may or may not be inevitable. Threats may be accompanied by strong negative emotions such as anger, fear, and resentment. Some examples of threats are worries about future health and functioning, aging, finances, a loved one experiencing difficulty, etc.
3. <u>Loss</u>: Damage that has already occurred, such as the death of a spouse, friend, or pet or an accidental injury that is accompanied by permanent functional losses. Loss could also refer to such situations as loss of a home or damage to a friendship.

Common locations:
Throughout interview.

Examples:

"It's a pain, but you learn to adjust to it. To me it's more stress. When I'm under a lot of stress, which I'm under a lot of stress right now, that keeps me awake more than the bowel/bladder issue…It's all work. Work and the good stuff, buying the house and getting the house remodeled. But mainly it's just so much work. And then we've got our core accreditation audit coming. I'm hiring two faculty, I'm starting a lab. All of that stuff that comes with running a department and just learning it all."

"The stress, the loads of stress, especially when you pay bills and they re-bill you for the same bill and then you gotta go back and call them and straighten them out. It's just insane. "

QUALITY OF LIFE: QOL REFLECTIONS

Definition:

SCI-Health-related life satisfaction refers to aspects of a person's overall well-being that can be clearly shown to affect and/or be affected by the presence of an SCI impairment and/or by past and current health status (physical, mental, or social). Life satisfaction (subjective QOL) refers to the individual's response to the "goodness of fit" between expectations and achievements, as experienced by the person, within a time perspective.

Components:

1. Expectations: is a label for the broad category of what should be goals, values, standards of comparison, desires, aspirations, wants and needs, etc.
2. Achievements: refers to what the person actually has, is, or controls, such as performances, accomplishments, possessions, relationships, etc. These achievements are held up to the expectations listed above
3. Emotional and/or cognitive response: The individual's assessment of the congruence or gap between his or her expectations and achievements e.g.:
   a. Happiness or sadness
   b. Satisfaction/ dissatisfaction
   c. Zest for life/depression
   d. positive/negative affect

Common locations:

- Section 4: Life course expectations
- Potentially throughout interview

Examples:

"I expect all that stuff to come back. That's my beliefs and my expectations for myself so I'm not letting it worry me right now. .I hope that I can get home and I can control that stuff so my wife doesn't have to deal with But it's just gonna take time. I'd like to be fully restored and retired and have time to go up north and enjoy my cabin and my property up there and go do the things I always wanted to do. Life in a wheelchair is rather difficult….[SCI] ….it hasn't beat me up at all; hasn't changed me a bit… I have to deal with it; we just make light of it and laugh about it here and there and it's… you just take care of business and get on with it" (UM-040).

"I've achieved everything that I wanted to achieve in my life and more. I've actually exceeded my expectations of what I thought my life would be. And to be honest with you, had I not had the spinal cord injury I don't know that I would be saying that. So I can really attribute where I'm at to the acquisition of my spinal cord injury" (UM-020).

"Well I never thought I'd be sticking a catheter into my bladder four times a day. I never thought I'd be sticking a finger up my bum every day either, but those are the realities of life now. I don't know if, they've just redefined, I don't think they've changed my professional, my spinal cord injury altogether changed my life goals. I planned on being a career military guy and now I'm data geek at a billion dollar company so, a little different" (VA-002).

QUALITY OF LIFE: SUBJECTIVE QOL RATING

Definition:
      This code refers to the specific question on Quality of Life that appears at the end of the interview and includes a numerical score.

Components:
1. Numerical score on QOL (1-10) rating scale
2. Reasons for numerical rating of QOL

Common locations:
- Section 4: Life course expectations

Examples:

      "Probably about a 7. Well I'm totally comfortable here at this facility. All the people are very good. They do their services to the people that are here pretty much on timely schedules and within an acceptable range of… as far as doing a complete job and on time. The facility here is just beautiful. People walk into my room; they can't believe how nice it is. All the furniture appointments and everything are really nice. I've got two recliner chairs in my room and a mechanical bed; TV with a real nice entertainment center and just about everything you could want for yourself. It's got a kitchen kind of thing. It doesn't have stoves in it but it's set up to actually take a microwave. As far as here, getting around, doing whatever you want to do has been real good and the people make it easier for you. They often will, if you're sitting in the hall or something, they ask you if there's something they can do for you" (UM-040).

      "I've got to give myself somewhere between a nine and a ten. I'm going to pick a nine because there's always room for improvement, but I would pick a nine because I'm totally empowered; I love what I do. I teach, I do research, I'm totally independent socio-economically and I'm pretty solid. My needs are met. I have pretty much everything that I wanted" (UM-020).

      "Let's see, if I won the lottery last night it would be a ten. I still have a job so it's not a one. Probably an eight or nine…because for the most part I'm pretty happy with the way my life is. Could it be better? I'm sure it could. I have a good job, I have a good wife, my kids are healthy, fairly intelligent, not killing each other yet. So yeah, for the most part life's pretty darn good. Could it be better? Sure, I could wake up tomorrow and have full bowel and bladder control. Not going to happen, but I could win the lottery. That'd be nice. My boss could wake up tomorrow and go, hey let's make you a, give you a promotion or give you a pay raise. Things could always be better" (VA-002).

SOCIAL FACTORS: SOCIAL ROLE PRIVATE

Definition:

      This code should be used for any talk around a person's role, relationship, or interaction with spouse/partner, children, family, caregiver and friends – in general, those with whom the participant has a direct, personal relationship; people that form part of his/her immediate personal-social network.

Components:

1. <u>General</u>: perceptions of private life, expectations, roles, relationships, interactions with
2. <u>Roles</u>: spouse/romantic partner, parent, grandparent, family member, friend, care recipient

Common locations:

1. Section 4: Social relationships
2. Throughout the transcript

Examples:

      "I would say that it's of course at differing levels. Let's start with family. Family, it hasn't really impacted at all as far as the relationships go. A couple of my sisters know how to cath me and are comfortable cathing me. It has impacted when I travel. Instead of being able to go and stay at one of my sisters' houses, I have to stay at a hotel because I have the nurses. Could I stay at their house? Probably, but access would be a problem, having the nurses there, so that's an issue there. Friends are cool. It's kind of weird because I'm always traveling with my nurse so I have a third person, but usually what happens is if I go out to the restaurant or the movies, the nurse will just drop me off and then come back and pick me up. I just text her, so then I am able to do a one-on-one with my friends because I don't drive" (UM-020).

      "Travel is a pain. I don't travel unless I absolutely have to. So that has really probably impacted my relationships with my family and friends in Michigan, Florida. If I didn't have the spinal cord injury I would probably be flying out five, six times a year visiting people. I just realized I went home for a family reunion in September and it was the first time I'd been home since I left Michigan" (UM-020).

SOCIAL FACTORS: SOCIAL ROLE PUBLIC

Definition:

This code should be used for any talk around a person's role, relationship, interaction, or perceptions of life outside of the home including work, community, or volunteering – in general, those with whom the participant has a more formal relationship outside their immediate personal network.

Components:

1. <u>Work</u>: relationships with coworkers, job responsibilities, career
2. <u>Community</u>:
3. <u>Volunteer</u>:

Common locations:

1. Section 4: Social relationships
2. Throughout the transcript

Examples:

"Oh, absolutely. It's never a question. I pretty much am able to plan my own schedule and I work pretty independently so I don't have a lot of situations where I'm running into a problem. But I'm fine telling people, "I'm sorry, I need a ten-minute break to use the bathroom," and they're fine with that, too" (UM-020).

SOCIAL FACTORS: SOCIAL SUPPORT

Definition:
      This code should be used for any talk around perceptions and discussions related to support or lack of support provided by others (family, friends, community, caregiver).

Components:
1. Friends
2. Family
3. Spouse (may often be double-coded with caregiver

Common locations:
1. Section 4: Social relationships
2. Throughout the transcript

Examples: